TITLE
Predictors of Burden of Care Among Caregivers of Drug-Naive Children and Adolescents With ADHD: A Cross-Sectional Correlative Study From Muscat, Oman.

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Predictors of Burden of Care among caregivers of drug-naive children and adolescents with attention-deficit/hyperactivity disorder: A cross-sectional correlative study from Muscat, Oman

ABSTRACT

INTRODUCTION: The psychological burden, or *the Burden of Care,* of caregivers of children with neurodevelopmental disorders - especially attention deficit hyperactive disorder (ADHD) - has been the subject of many studies worldwide. From the Arab/Islamic countries there is a dearth of research on the burden of care. The present study attempts to rectify the omission by assessing the prevalence of the burden of care among caregivers of children with ADHD in Oman.

OBJECTIVES: The study assesses the prevalence of burden of care among caregivers of children who had been diagnosed with ADHD seeking consultation at a tertiary care unit in Oman. Related aim is to explore the predictors of the burden of care, subtypes of ADHD and socio-demographic factors.

METHODS: Across-sectional correlative study was conducted in a tertiary hospital in Oman that provides child and adolescent mental health services. Arabic-version of the *Zarit Burden Interview* (ZBI) was administered to 117 caregivers of drug-naive children with ADHD attending a tertiary care hospital in Oman with child and adolescent mental health services. Socio-demographic background and clinical data were gathered from medical records as well as directly from the attending caregivers. The ADHD symptoms were grouped as hyperactive, inattentive or mixed.

RESULTS: The prevalence of the burden of care was estimated to be 34%. Binary regression analysis indicated that factors such as income levels of the caregiver as well as the child's ADHD being of "mixed" type have significant impact on the burden of care.

CONCLUSION: The results of this study indicate that the prevalence of the burden of care among the caregivers of ADHD children in Oman is comparable to that in the other regions of the world. Our results showed lower income sole caregiver and the type of ADHD to be significant predictors of burden of care. As the caregivers' psychological stress impact the wellbeing of the family, and the society as a whole, the issue of the burden of care needs to be studied further detail and interventions evolved.

KEYWORDS: Attention-deficit/hyperactivity disorder; Burden of care; Zarit Burden Interview; Caregivers; Oman; Arab/Islamic

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterized by inattention, impulsivity, and hyperactivity [1, 2]. Previously taken lightly as an 'American condition' [3], ADHD is now recognized as one of the most common neurodevelopmental disorders and affects 1–7% of children and adolescents worldwide [4, 5]. The prevalence rate tends to vary depending on whether the identification was based on Diagnostic and Statistical Manual of Mental Disorders criteria or International Classification of Diseases criteria [6]. ADHD is known to be marked with high rate of co-morbidities [7, 8]. More than typically developing children, ADHD children tend to manifest both externalization and internalization of behavior problems [9,10] which, in turn, dictate variations in adaptive skills, academic and social competency [11,12].

While various aspects of childhood ADHD such as signs and symptoms, associated disorders, etiology, pathophysiology, diagnosis, management, prognosis and epidemiology have received wide attention in literature [13], the question of the burden of care on the parents has received due attention only recently. Barroso et al [14] reviewed the existing literature and concluded that parenting stress was strongly related to the child's externalization of ADHD symptoms resulting in disruptive behavior [15, 16]. Another recent large scale study conducted among caregivers of children with ADHD in ten European countries reported that the most significant burden of care was related to strain on daily family life, exclusion from social activities, negative impact on work, and parental stress [17]. In another related study, the majority of caregivers reported difficulties with their family relationships, social life, continuity of education and occupation. An Australian study found a strong correlation between poor quality family functioning and child ADHD [18]. In the United Kingdom, [19] in an observational study of 91 families caring for children with ADHD reported the caregivers exhibiting high burden of care. Davis et al's [20] qualitative study among 28 families in Boston, USA, clearly indicated that having a child with ADHD led to strained family relationships and functioning. Wakimizu et al. [21] found high burden of care among caregivers in Japanese families with ADHD children. From Africa, a Nigerian study yielded similar results [22].

In addition, the heightened challenges of living with a child with ADHD have been linked to a higher incidence of mental health difficulties in the whole family nucleus and a consequent increased use of healthcare services by the whole family [23]. In particular ADHD in the child has been associated with a more severe risk of parental depression and alcohol related disorders [23].

Studies have also explored factors that might trigger the burden of care. Barahmand Piri & Khazaee [24] reported from Malaysia that caring for children with ADHD who were also marked with lower functioning may trigger elevated scores in indices of the burden of care. Theule et al. [25] conducted a meta-analysis of 22 published and 22 unpublished studies that focused on the challenges faced by caregivers of children with ADHD, and suggested that caregivers of children with ADHD tended to experience higher levels of parenting stress than parents of typically-developing children.

As cited above, the presence of psychological burden in caring for children with developmental disorders is now well-documented from various parts of the world, except from Oman and other Arabian Gulf countries. Regarding prevalence of ADHD in Oman, two preliminary cross-sectional studies have suggested that 5.1% of all girls and 7.8% of all boys in Oman are exhibiting the symptoms of ADHD [26, 27]. Oman has a pyramidal population structure with the bulk of the population are in the pediatric age group [28]. The current cross sectional analytical study aimed to assess the prevalence and predictors of caregiver burden among caregivers of children with ADHD who sought consultation at the Children and Adolescent Mental Health (CAMH) Clinic in a tertiary care facility in Muscat, Oman.

Assessing the psycho-social burden of caring for a child with ADHD appears crucial in order to develop and deliver targeted systemic interventions that take into consideration both the direct impact of the condition, but also the more indirect effects. In fact, the literature highlights how the burden of ADHD has significant financial implications on the family and the larger system [29]. In an analysis of the increment of total expenditure for people with ADHD in the US, the researchers reported increased medical costs for both patients and families and increased costs on society related to caregivers' absenteeism and reduced productivity in the workplace. As Oman moves closer to a "post-oil" economy and increases its economic diversification, it is

crucial to explore ways in which its citizens can be supported to achieve wellbeing. This, in turn, will have an impact on the country as a whole.

Methods

Study design

This cross-sectional and correlative study was carried out at a Children and Adolescents Mental Health (CAMH) Clinic at Al Massarah Hospital in Muscat, Oman between March and June 2017. Al Massarah Hospital is the largest tertiary care for mental health center in the country. It accepts referrals from various secondary care mental health departments across Oman. Healthcare in Oman is free for all nationals, and it has been centralized and compartmentalized. For all the reasons above, the authors selected Al Massarah Hospital to study the burden of care among caregivers of ADHD children. To report this study, the authors have followed the recommendations of STROBE reporting guidelines [30]. The issue of inclusion and exclusion as well as diagnosis of ADHD for the present study have been detailed elsewhere [31]. The children with ADHD had been referred to this tertiary care clinic from either school or primary healthcare centres, after an initial diagnosis made using symptom checklist, Conners Teacher Rating Scale [32]. At the tertiary care, the assessing child and adolescent psychiatrists, who were blind to the performance of psychosical measures of the parents, administered a semi-structured Composite International Diagnostic Interview (CIDI) to children to aid in the diagnosis of ADHD. Children with other co-morbidities those with IQ <80, and those who were currently on psychotropic medications were excluded from the study sample.

Study sample and sampling method

To calculate the optimum sample size, the EPi Info Software was used after considering the power at 80%, type one error at 5% and confidence interval of 95%. After assuming a likely prevalence rate of burden of care of 41% (as per previous studies), the total number of ADHD children and adolescents, and the likelihood that their caregivers would repeat their visit to CAMH clinic over a three month period (total population; N=205 caregivers), the required sample size was n=135 to determine the period prevalence. Caregivers aged 20 – 65 years who consented, and were attending the CAMH clinic, were eligible to participate in the study.

Caregivers who were illiterate, those who suffered from severe medical illnesses, and those who did not provide their consent were excluded. A systemic random sample (every 2nd care giver) method was adopted to recruit the study sample. Any recruited participant who did not meet the inclusion criteria was excluded and replaced by the next potential participant.

Outcome Measures

The Zarit Burden Interview (ZBI)

The ZBI was developed in 1985 to measure the burden of a care among caregivers of people with cognitive disorders [33] as well as well as other chronic and refractory conditions [34,35]. ZBI has been adopted in different cultures and languages and have shown consistent utility despite the differences in the factor structure [36]. ZBI is 22-question tool that measures caregiver burden and all questions are answered on a five-point Likert scale (that ranges from "never" equaling "0" to "nearly always" equaling "4") . The sum of the individual item scores results in a global score ranging from 0 to 88, with higher scores signifying a greater burden as perceived by a caregiver. In the current study, we used the Arabic version that was adopted in a study conducted among Saudi participants [37]. However, factor analysis had not been done in that study to evaluate the validity of the Arabic translation. Hence, to assess the construct validity of the Arabic version of ZBI, we carried out an exploratory factor analysis using Generalized Least Squares along with oblique rotation in the present study sample. The reduction analysis resulted in three factors with an eigenvalue greater than 1 and accounted for 63.6% of the total variance. Those factors were labeled as follows: *factor 1:* "Social constraint" (eight items); *factor 2:* "Negative self-appraisal" (five items); and *factor 3:* "Annoyance" (nine items). Correlation between factors 1 and 3 was much higher ($r = 0.8$) than the correlation between factors 1 and 2 ($r = 0.54$), and between factors 2 and 3 ($r = 0.42$). The Internal Consistency Reliability of Arabic translations of ZBI was found to be good in our study with Cronbach alpha of 0.8. For the purpose of calculating the prevalence rate, participants with ZBI global score of >21 were deemed as enduring significant burden. The severity was classified according to the global score as follows; 0–20, no or little burden; 21–40, mild to moderate burden; 41–60, moderate to severe burden; and 61–88, severe burden [38].

Additional data, namely, the care-provider's age, gender, marital status, educational level, occupation, monthly income, region of residence in Oman, number of children, presence of a

sibling with similar condition, the child's age group, gender and ADHD type (hyperactive/impulsive, combined or inattentive), were gathered in addition to ZBI scores.

Process of data collection

Data collection and administration of the study tool took place while the caregivers werewaiting for their appointment to meet the child psychiatrist at the clinic. Those who consented were provided with a private room to answer the questionnaire. In case more time was needed, the participant completed his response after the session with the psychiatrist. The investigators informed all participants, verbally and in writing, that their participation would be confidential, that they had full autonomy to enroll in the study, and that they could withdraw from the study anytimewith no prejudice. In accordance with the Beneficence principle in research, the enrolled participants who scored significantly higher on items that measure depression were counselled regarding further option of referral for a comprehensive psychiatric assessment.

Ethical Approval

This research adhered to the guidance of the World Medical Association's Declaration of Helsinki (1964–2008) for Ethical Human Research entailing participant's confidentiality, privacy and handling of study data [39]. The work has been granted an ethical approval by Oman Medical Specialty Board Research Ethics Committee (MH/DGPS/MG101).

Statistical Analysis

Data were analyzed using SPSS software, version 22.0 (IBM Corp, Armonk, NY, USA) [39]. Socio-demographic and clinical variables were presented as percentages and frequencies.

Goodness of Fit Index with a cutoff score of >0.9 was considered to reduce the probability of type 1 error in the process of running an explanatory factor analysis of the data in the current study. To test the suitability of the data for factor analysis, Bartlett's test and the Kaiser-Meyer-Olkin (KMO) index were used and then followed by the varimax rotation approach. For an item to be considered belonging to a certain factor, its factor loading should be more than 0.40.

The prevalence rate was calculated as a percentage of those with ZBI scores of more than 21, out of the whole study sample. In univariate analysis, the chi-squared test (χ^2) was utilized to explore the associations (by calculating the proportions) between the socio-demographic and clinical factors and the presence of Burden of care as an outcome (dependent variable).

To investigate the predictors of the burden of care and to adjust for potential confounders associated with both exposure and outcome, a stepwise backward binary logistic regression analysis was carried out for the variables that were significant at univariate level. Covariates were selected after considering their potential relationship with independent variables and likelihood of reporting significant burden of care (by univariate analysis (p=0.25). The unadjusted and adjusted odds ratios were presented in univariate and multivariate analysis with a 95% confidence intervals (95% CI). The Good of fit for the logistic regression model was gauged using techniques described by Cox and Snell [41].

Results

Insert Table 1 about here

The Table 1 presents the socio demographic and baseline characteristics of the study subjects. A total of 117 participants returned filled questionnaires out of 135 required participants, giving a response rate of 87%. Of the 117 subjects studied, the mean (sd) of age was 35 (5.12) years and 82% were women. About 96% of the participants were married. About half the participants had high school education while the rest had post-graduate degrees. The majority were employed and two third belonged to higher income group. Sixty percent of the care givers had up to 4 children and 17% had siblings with the similar condition. Three quarters of the ADHD affected children were boys. Among the ADHD affected children, 60% were diagnosed as hyperactive, 26% mixed and the rest inattentive.

Insert Table 2 about here

As Table2 depicts, the prevalence rate of the burden of care (Zarit score >21) was about

34% of the 117 caregivers enrolled in the study. Almost half of the caregivers endorsing significant burden reported severe levels of burden of care (ZBI >40).

Insert Table 3 about here

Table 2 presents the bivariate (unadjusted) and multivariate (adjusted) analysis results of the burden of care with different factors. In the bivariate analyses gender, educational level, occupation, income groups and those who had assistance from other caregivers were shown higher odds and statistically significant for endorsement of the burden of care. However, in multivariate analyses, after adjusting for other factors, lower income was a significant predictor of the burden of care OR 232.97 (95% CI 14.80-3668.50, p<0.001). Those who cared for children with mixed type ADHD were more likely to endorse the burden of care OR 12.01 (95% CI 1.33-108.12, p=0.027). Variables such as gender, location of residence and level of education showed higher adjusted odds ratio but were not statistically significant.

Discussion

With high population growth, historically low child mortality, and rapidly changing lifestyles, Oman has a rising number of children with cognitive, emotional and behavioral disorders [42, 43], among which ADHD is the most prominent [44-46]. ADHD needs to be understood and managed within a biopsychosocial paradigm that gives cognizance to the interaction between biological, psychological, and social variables [47] – particularly those impacting the quality of relationship between the caregiver and the child. Existing remedial and rehabilitation initiatives focus on the child, overlooking the suffering of the caregiver. Within such background, this study has embarked to quantify the prevalence and predictors of the burden of care among caregivers of children with ADHD who sought consultation at the Children and Adolescent Mental Health (CAMH) Clinic in a tertiary care facility in Muscat, Oman.

The prevalence of the burden of care was solicited using *the Zarit Burden Interview* (ZBI)**.** The present data suggest that the 34 % of the caregivers endorsed ZBI scores of >21. It is noteworthy that the prevalence of burden of care in the current study is lying outside the pre-specified confidence interval. This could be explained by the differences in the ZBI cutoff scores

used to define burden of care by regional and international studies. Various studies have explored parallel concept of burden among caregiver of children with ADHD including quality of life [48-51], psychological disorders [52]. These studies do suggest that caregivers of children with ADHD tend to endorse high levels of burden compared to controls [53]. While our results appear to be in consonance with previous studies, it is important to note that the children in the present study were not yet medicated. This finding therefore adds another twist in the literature as to whether ADHD children in those studies were already on medication. Otherwise, the outcome in term of burden of care appears to be the same.

Within such background, this study has embarked to examine the factors predicting the presence of the significant burden of care among the caregivers. In the present study, hyperactive/impulsive and combined types of ADHD were significant predictors of the burden of care among the caregivers in the multivariate analysis. A study by Beck et al. [54] found that the mothers of children with ADHD hyperactive subtype experienced more stress and burden compared to other subtypes. Samiei et al. [55] have reported high perceived burden among caregivers of children with hyperactive subtype as well. Other studies have also indicated that externalization behavior problems such as those stemming from hyperactivities and impulsive behaviors tend to drain wellbeing of the caregivers [56, 57].

Gupte-Singh et al. [29] and Lesesne, Visser & White's studies [58] among the US population have reported that mothers with children with ADHD on one hand, tend to have financial difficulties and, on the other, they are more likely to utilize the health care system. Studies in the US have indicated that health care cost for children with ADHD tend to be higher than for matching controls [59]. Higher health care utilizations have been linked to the children's lower impulse control and the resultant increased risk of unintentional injury [60], but also to a decrease in mental health wellbeing in the caregiver [23] In addition to the link between hyperactive/impulsive and combined types of ADHD and burden of care, the multivariate analysis in this study also suggested that lower income is significantly related to perceiving high degree of burden of care. Despite being a high income country with a generous welfare system that provides free education and health care services from cradle to grave, recent affluence has eroded traditional social networking as urbanization increases the number of nuclear families. Previous studies focusing on other types of neurodevelopmental disorders in Oman have found that the presence of a child with special needs and talents often impairs the family's social

mobility [42]. Among the general population of Oman, there is evidence to suggest that stress levels are higher among those classified as belonging to low-socio-economic status [61] which is also endorsed by the present study. This finding could partly be explained by the caregiver's absenteeism and loss of productivity in the workplace. In fact, it can be speculated that taking time off work to take care for the children and/or to accompany them during physician' visits would concern and impact more significantly on individals from lower SES who might be more affected by potential loss of earnings.

We did not find any significant association between caregivers' burden and the other socio-demographic variables in the multivariate analysis after adjusting for other factors. This seems partially in contrast to a study from Jordan that reported a positive, significant relationship between age and levels of depression in parents of children with ADHD, as well higher levels of depressive symptoms in couples who had been married the longest [62]. Whilst a causative relationship between ADHD and levels of depression and age/time cannot be corroborated at present, it is reasonable to speculate that the burden of care that families have to endure as a result of caring for someone with hyperactivity might intensify symptoms of depression in caregivers [63; 64]. Hence the possibility that the burden of care might act as a causal factor for the deterioration of caregivers' mental health ought to be investigated further.

Overall, this study suggests that the burden of care is common among caregiver attendees to CAMH and that externalization of the ADHD child's behavior problems as well as being in the lower income strata increase the burden of care. Hence, in order to maximize the cost effectiveness of treatment, future interventions for children with ADHD ought to be rooted in the family as a whole. Al Sharbati et al.[44] recommend a multidisciplinary approach to the treatment of ADHD and a variey of interventions that focus on social and occupational factors, as well as psychological and educational. The present study confirms the need for more a holistic and systemic approach that places the family and the larger context at its forefront.

Limitations

Studies such as this are likely to be marred with several limitations. The most obvious ones are highlighted here. In the first instance, it is noteworthy that less people than the number indicated by the preliminary power calculations were recruited. This ought to prompt caution in the

interpretation of the results. Secondly, those who have sought consultation from this particular tertiary care with dedicated CAMH might be a self-selective group in terms of income and severity of ADHD symptoms. They may also be more exposed to modern knowledge and thus less stigmatized by seeking mental health care. Future studies should be conducted in wider community in order to gauge even those children with ADHD who might not have severe symptoms.Furthermore,, although Oman has a centralized and compartmentalized health care system, it is possible the present cohort may represent those who can easily find access to the present tertiary care. Therefore, the generalization of the present finding to the rest of the country must be taken with caution. Finally, the present cohort is marked with depressive symptoms as testified by previous publication [55; 62]. Two considerations are worth at this stage. On the one hand, it is well known that depressive illness tends to impair one's ability to recall accurately and is also marked with 'catastrophic thinking' [65].Therefore future studies need to verify the validity of such endorsement in indices of the burden of care. On the other hand, as mentioned above, the possibility of ADHD exacerbating caregivers' mental wellbeing ought to be taken into consideration and investigated further. **Conclusion**

The present study explored the burden of care among caregivers of drug naive children with ADHD and found it to be prevalent. Among the correlates of the burden of care include those ADHD marked with real core symptoms of ADHD - impulsivity, inattention and hyperkinetic disorders. Our findings do imply that there is more to ADHD than the afflicted children. There is a need for a more an integrated bio-psychosocial approach to ADHD to reduce the level and degree of burden among unsung victims of ADHD.

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Table 1: Distribution of clinical-socio-demographic variables of the caregivers and their ADHD children (n = 117)

Variables	n (117)	%
Age (Mean±SD)	35.39±5.12	
Gender		
Male	21	17.9
Female	96	82.1
Marital status		
Married	112	95.6
Divorced / Widow	5	4.3
Education level		
High school	61	52.1
Post Graduate	56	47.9
Occupation		
Unemployed	50	42.7
Employed	67	57.3
Income group		
Lower	36	30.8
Higher	81	69.2
Type of Location		
Rural	31	26.5
Urban	86	73.5
Number of Children		
Up to 4	70	59.8
>4	47	40.2
Presence of a sibling with similar condition		
Yes	20	17.1
No	97	82.9
Child age group		
Up to 8 years	68	58.1
> 8 years	49	41.9
Gender of the child		
Male	88	75.2
Female	29	24.8
ADHD group		
Hyperactive	70	59.8
Inattentive	17	14.5
Mixed	30	25.6

Table 2 Prevalence rate and Distribution of severity of the burden of care according to Zarit Burden Interview score

Severity level	n (117)	%
Zarit Burden Interview Score		
No burden (≤ 20)	77	66
Mild – Moderate (21-40)	21	18
Higher burden (>40)	19	16

Table3: Binary Logistic regression analysis for predicting the odds ratios (adjusted and unadjusted) of the presence of the burden of care (ZBI >21) from the potential explanatory and associated independent variables

Variables	Having Burden (n = 40)	Unadjusted analysis			Adjusted analysis		
		OR	95% CI	p - Value	OR	95% CI	p - Value
Age group							
<35 years	21 (52.5)	1.39	0.65-3.0	0.392			
≥35 years	19 (47.5)	1.0					
Gender							
Male	3 (7.5)	3.76	1.04-	0.044	8.68	0.80-94.39	0.076
Female	37 (92.5)	1.0	13.66				
Education level							
High school	32 (80.0)	6.62	2.69-	<0.001	0.57	0.74-4.38	0.588
Post Graduate	8 (20.0)	1.0	16.31		1.0		
Occupation							
Unemployed	29 (72.5)	11.86	4.81-	<0.001	1.73	0.15-19.31	0.658
Employee	11 (27.5)	1.0	29.29		1.0		
Income group							
Lower	29 (72.5)	26.36	9.30-	<0.001	232.97	14.80-	<0.001
Higher	11 (27.5)	1.0	74.72		1.0	3668.50	
Type of Location							
Rural	11 (27.5)	1.08	0.46-2.56	0.767	2.23	0.48-10.45	0.309
Urban	29 (72.5)	1.0			1.0		
Other caregivers							
Yes	13 (32.5)	1.0			1.0		
No	27 (67.5)	6.81	2.92-	<0.001	0.91	0.18-4.44	0.902
			15.87				
Number of Children	24 (60.0)	1.01	0.46-2.20	0.978			
Up to 4	16 (20.0)	1.0					
>4							
Child age group							
Up to 8 years	23 (57.5)	0.96	0.44-2.09	0.922			
> 8 years	17 (42.5)	1.0					
Gender of the child	32 (80.0)	1.0					
Male	8 (20.0)	1.5	0.60-3.78	0.389			
Female							
ADHD group							
Hyperactive	9 (23.1)	1.0			1.0		
Mixed	30 (76.9)	1.75	0.70-4.36	0.230	12.01	1.33-108.12	0.027